

UTAH NEWBORN HEARING SCREENING ADVISORY COMMITTEE

Next Meeting February 11, 2014

November 12, 2013 meeting minutes – **DRAFT** – approval vote to be done Feb. 11, 2014

In attendance: Krysta Badger, Kelly Dick, Catherine Hoelscher, Nita Jensen, Katie Jolma, Jamie Kolgen (Guest, nursing student attending with Sylvia White), Charlene Frail-McGeever, Stephanie McVicar, Taunya Paxton, Michael Page, PCH Audiology Manager (Guest), Paula Pittman, Harper Randall, Kurt Randall, Lori Ruth, Sharon Strong, Sylvia White, Shannon Wnek, Erin Zinkhan

Excused: Susie Bohning, Karen Munoz, Albert Park, Kathleen Pitcher-Tobey, Suzanne Smith, Jill Vicory, Karl White

WELCOME

Dr. Kelly Dick opened the meeting at 9:05. Members as listed above were excused from today's meeting. Introductions were made.

Dr. Dick acknowledged the retirement of Dr. Richard Harward as the Bureau Director of the Utah Department of Health's Children with Special Healthcare Needs. Dr. Harward attended this meeting as a "staff member", so no additional committee member will replace him.

A motion was requested to approve the August minutes. The motion carried with all in favor and with no one abstaining.

Committee seats were discussed as several individuals are at the end of their tenure; Sylvia White (Early Intervention, will continue), Kathleen Pitcher-Tobey (Insurance, will not continue), Jill Vicory (Utah Hospital Association, may continue), and Dr. Albert Park (ENT, will not continue). Representatives for certain disciplines and areas of care are required on this committee, others are by invitation. Sylvia White has approval to continue in her position for another four years. It was unanimously approved, with no one abstaining to have Sylvia White continue as the Public Nurse Representative for this committee. Dr. Harper Randall suggested a few names for ENT's for the committee to review. Voting will take place at the February meeting. All bios are available online: Dr. David Parker Hill – Otolaryngologist, practices at Intermountain Clinic; Dr. Steven Miller – Otolaryngologist, ENT Center in SLC; Dr. Jeremy Meir – Otolaryngologist, PCH ENT clinic; Dr. J. Frederick Grimmer – PCH ENT Clinic. We need to determine who will be a good fit here and provide the insight that the Committee needs. Dr. Randall personally knows two of these candidates, but thinks the best fit for the committee will be to have someone who is focused on pediatrics. Dr. Mike Page knows all four of these candidates, but would like to know to what degree we want someone that will be a champion for the message going out. He thinks the pediatric folks are already on board and it might be good to have a non-pediatric representative that would take the message and get it out. Dr. Randall suggested Dr. Miller and Dr. Hill because she refers patients to them a lot. Dr. Katie Jolma refers to Dr. Brian Tagge. Sylvia noted that many of her kids see Dr. Grimmer and the parents seem happy with him. Erin Zinkham said that her nurses work with Dr. Grimmer and Dr. Meier often. No one from this list has been contacted yet. We will also accept other candidates. Dr. Dick agrees with Dr. Page that we need to get someone who will advocate and be willing to help support Committee needs on the view from the ENT. Dr. Meier is already on the Hearing Aid Advisory Committee. Dr. Grimmer is friends with CSHCN and is involved in the multidisciplinary clinics with this Bureau. Nita Jensen will contact Dr. Park for his assistance in recruiting for this position. Charlene Frail-McGeever will make sure the candidates are on the Medicaid and CHIP panels.

Primary Children's Hospital (PCH) representation was discussed. There has been a representative from PCH on this committee in the past, which is why Dr. Page was invited to attend today. PCH is such a key provider of pediatric care in the state. Nancy Hohler was the previous PCH Representative. When she changed positions we did not replace her. There is a proposal to replace her position as a voting member with Dr. Page. Dr. Page would be happy to fill the position, but would like to know if it would be better to have Adrienne Jackson, an active audiologist who participates in NBHS attend in his place. Dr. Page's role at PCH is to manage the Audiology Department and Cochlear Implants; he is not clinically active doing newborn hearing screenings. Kurt Randall noted that we already have Dr. Susie Bohning on the committee to provide a clinical perspective; it would be nice to have Dr. Page attend in order to provide the global perspective. If Dr. Page is unable to attend a meeting, he can send Adrienne in his place.

Please let the committee know if you have ideas for an insurance representative who can take Kathleen Pitcher-Toby's position on the committee. Kathleen mentioned to Nita that she can check into possible candidates with Blue Cross Blue Shield. Charlene questioned if we could approach someone from SelectHealth, since they are a commercial insurer. Nita noted that previous representative, Jim Wilson, was employed by SelectHealth and that was a beneficial collaboration. Charlene will see if there is anyone that serves both populations that might be interested. She will get back to Nita on that.

Public Comment

No comments.

26-10-10 CMV Rule update/26-10-11 Children's Hearing Aid legislation & Rule

Dr. Stephanie McVicar discussed the CMV Law update. The Administrative Rule (which helps define the law) is almost ready to be posted for public comment. One issue presented by Dr. Jolma is how the NICU population should handle having two hearing screenings done to facilitate the CMV screen before 21 days. There is a "special populations" clause in the proposed Rule that does state that there are certain populations of newborns that may be unable to have two hearing screens and that the CMV test is left to the discretion of the medical provider. The Rule has been approved by legal and is currently waiting for approval by Dr. Patton before it will be posted. The proposed Rule should post for public comment December 1 and be open for comment for thirty days. Nita will send a notification to this committee once they are up for comment. Dr. McVicar has upcoming CMV training presentations scheduled and is willing to do more if there is an audience that would like her to speak. She has used the Tele-medicine hub at the University of Utah to speak with school nurses, she would be glad to present to any group requesting training. Please direct anyone with CMV questions to Dr. McVicar.

A National CMV Public Health and Policy Conference is scheduled in Salt Lake at the Little America Conference Center on September 26th and 27th, 2014. The planning committee includes Dr. Karl White, Dr. Park, Dr. Jim Bale, Sarah Dautre and Representative Rhonda Menlove. Experts on CMV and CMV research will present. Targeted tracks for families, researchers and public policy advocates are planned. The conference is hosted through the National Center for Hearing Assessment and Management at Utah State University (NCHAM). More information is available at www.infanthearing.org. A call for abstracts will be distributed soon. The annual State EHDI Conference for Utah hospital programs will be held at UDOH CSHCN on September 25th.

A CMV Policy update should be sent to the AAP Growing Times Newsletter and by email blasts to the AAP and Family Practitioners Association. Since July 1, 2013, when the CMV law became effective, we have had four fax back forms received at the State EHDI office for positive congenital CMV tests, 18 children tested and negative, 1 refused testing. HiTrack shows seven infants with positive CMV results reported. One big need for

the CMV mandate is better documentation in HiTrack. The Rule has reporting requirements as State EHDI will need to report to the legislature each year.

The application/eligibility process for the Children's Hearing Aid Pilot Program (CHAPP) has been delayed due to the \$100 enrollment fee that their advisory committee proposed (to elicit family buy in). Representative Becky Edwards supported this fee, but the way the mandate is written does not allow us to charge a family fee. It is possible that the fee can be reconsidered next year. Five families have applied and been approved for CHAPP so far, but until the fee issue is resolved, no funds can be released. Dr. McVicar will send out an email once the link to the forms has been posted on the website. Families are eligible for CHAPP for income up to 300% of the federal poverty guidelines, (\$70,000 range for a family of four), and the child has not reached his/her 3rd birthday. This program will also cover the managing audiologist who will be paid for the cost of the hearing aids plus 40%. Previous UDOH programs did not reimburse the audiologist for their time, which could be a reason the programs were not utilized. Remaining hearing aids from the Early Fit program will now be available through HARP for children over the age of three. Answers to frequently asked questions are on the website. Please contact the UDOH with other questions.

EHDI HRSA Loss To Follow-Up Funding

We have received the funding opportunity announcement for the EHDI HRSA Loss to Follow-up Grant. This grant is State EHDI's main source of funding and the current three year cycle ends March 31, 2014. The grant application is due through Grants.gov on December 27th. This funding opportunity is focused on Quality Improvement (QI). A new committee for QI will need to be created as a grant requirement. A plan to reduce LTFU by five percent annually is required to get these funds. If anyone would like to be on the QI committee please let us know. The funding amounts available for this cycle is \$250,00 per year (down from \$300,000 per year for the current grant cycle).

EHDI Updates

The annual Utah EDHI Conference was held in September. The focus was on CMV and how the hospitals were to implement the requirements of the law. There were 49 attendees including one midwife from a birthing center.

Nita discussed HiTrack issues and updates. Because of the Medicaid breach we have new security requirements to encrypt servers storing restricted health data. They have added another layer of security, called Guardiam, which must be installed on both state HiTrack servers. HiTrack is already encrypted and Nita oversees the secure passwords, plus this new added layer must go through IT. State IT has received input from the NCHAM HiTrack developers and it is hoped that the additional security will not negatively impact speed and service.

Programmers at NCHAM have been enlisted to create a CMV module for HiTrack that will enable screeners to add the required CMV data items into HiTrack. There are ten items that will be added, the same items that are currently reported on the fax form (ie: test ordered, when sent, what type, result). Screeners will be able to check boxes, dates, doctors, etc. Nita does not know when the first edition will be ready to review, but all the final details went to the programmers last week. This module will be included in all HiTrack databases at the hospitals. Midwives are still not using HiTrack, but they are submitting CMV referral forms when the babies refer on the hearing screening.

Issues regarding HiTrack Web were discussed. Currently 30 hospitals are using HiTrack Web. Many of the larger hospitals (IHC, McKay Dee) are not. The issue that has been brought to Dr. Dick's attention is that updates to individual records in HiTrack web are taking 30-60 seconds each. The net affect and the debt of time are very cumbersome. Nita noted the Core and the RAM were increased a few months ago to resolve this

problem, but the speed did NOT increase with these additions. Nita will make it a priority to talk to NCHAM and State IT again about this. NCHAM staff were included on phone calls with State IT for these updates so the process was done correctly on their end. Nita also mentioned that many times hospital do have additional screening results that are not in State HiTrack. We need to find a better answer for this. Dr. Dick was concerned last meeting because of the inconsistencies in data from their hospitals compared to the state's data. He doesn't know where the pitfalls are but they are trying to track it carefully at the facility. It would behoove other hospitals to go back and go through their data (tracking reports are sent to hospital coordinators every 4-6 week for comparison). It would also be good to know who is contacting the physicians with results. Dr. Jolma questioned how the screeners get CMV results back from the primary care provider (PCP). The physician is to fax the completed CMV form back to the birthing hospital as well as the UDOH. The reporting rule indicates that the PCP must notify the UDOH, but they do not have to notify the birthing hospital. The screeners have a form that they fax to the PCP (CMV fax-back form) at the time of the failed first screen and then again at the second failed screen when the CMV PCR referral is required. The PCP is requested to fill out the bottom of the form (positive/negative, urine/saliva) and fax back to the screening program and the UDOH. The Administrative Rule is currently open for comment so this could change based on the public comment. It would be nice to get an article in UAP as to what to do if there is a positive CMV result (the deadline for Growing Times is early December).

Hi-Track Data review/Out of Hospital births review

There are eight hospitals that have not been meeting rescreen percentages. We are contacting each hospital to make a plan to resolve this. We have three hospitals that have some outstanding problems; one in Cedar, one in Tooele, one in Blanding. These are always hospitals of concern. EHDI staff members who are assigned to these hospitals will coordinate with hospital coordinators to create an improvement plan. Every 4-6 weeks the Hospital Coordinator receives a HiTrack report (from State EHDI) of the babies we are tracking from their hospital. They should be cross checking that with their data. We need to come up with a plan to get these hospital coordinators to be more pro-active.

At our last committee meeting it was suggested that we look more deeply into why the numbers for out of hospital births are at 72%. Suzanne Smith, director of Bella Natal/Better Birth is on our committee and has volunteered to look into this issue with us. She is our inside source on midwives and shared some thoughts she has on our weaknesses:

- 1) We have midwives with access to machines that aren't screening, and we need to understand why.
- 2) We have midwives who don't appear to have access to machines (or at least, not very direct access), and we need to understand what is preventing them from referring clients to screening resources in their area. In some cases, this may be a dearth of resources. Or, the problem may be a lack of understanding of the law or the importance of screening. There may be relationship issues that are keeping midwives from sharing equipment. Or the problem may not be in the midwives at all. It may be in the clients, who have their own barriers to obtaining the screening when it cannot be done at a routine postpartum visit with the midwife.
- 3) There appear to be some areas in which no midwives have machines, and there are few other resources available for screening, especially resources that are economical. We need to figure out how to improve availability in these areas.

It is also entirely possible that there are reasons midwives don't screen that are not related to availability of resources. Political and social factors, for example, can be the most difficult problems to solve. Our intent is to identify the true barriers to screening before pursuing solutions. In doing so, we'll go for the big impact solutions first (focusing on midwives who are doing the most deliveries and missing the most babies, rather than the midwife who delivers 1-2 babies a year).

We have pulled all the data for home births from January 2012 and sorted the midwives by region and working groups. We will begin contacting the midwives with the most annual births. Dr. Randall mentioned the

possibility of doing a survey to the midwives. Suzanne Smith offered to make calls to the midwives. One of the barriers could be the state oversight, as we could be perceived as an intrusion. By having someone who isn't perceived as being a regulator call and ask a specific list of questions we may get better participation. Are there any other ideas on addressing this population? Dr. Dick thinks that we are on the right track and identifying key individuals who can address this and Dr. Randall's suggestion of having it come from the inside is good. We would like to regionalize the midwives and select a team leader of each group. There is a willingness to participate, so more educational opportunities may be key. Access to equipment has increased with 17 machines distributed to midwives throughout the state. Not all midwives "play well together" so there are some who work right next to each other that will want their own equipment. Suzanne will be invaluable knowing what midwives to group to share equipment. Taunya Paxton thinks it would be helpful to explain to parents that without early screening, it could take a long time for parents to realize that their child has a hearing problem. Dr. Jolma noted that for a parent to be concerned they need to be educated and it is the person taking care of them while they are pregnant who should be educating those parents. We will look in to presenting at the midwife conference in March 2014. Dr. Shannon Wnek recently completed a pre-natal brochure on NBHS/CMV that is ready to be printed. Letters have been sent out to every OB/GYN in the state to offer this brochure. It was noted that ALL midwives should be offered this brochure also.

National EHDI Update/NCHAM Activities

Dr. White and Karen Munoz are not in attendance today, so this agenda item will be updated in February 2014. The Annual National EHDI Conference will be held April 13-15, 2014 in Jacksonville, Florida. Details are available at <http://www.infanthearing.org/meeting/index.html>. Dr. White will update this committee on the September CMV Conference at the next committee meeting in February.

Family to Family Support

Taunya Paxton updated the committee on Family to Family Support activities. They are trying to utilize resources we have in the state already. She has been in contact with Steve Noyes, current head of Utah AG Bell Assn. He plans to contact Utah Hands and Voices to discuss collaboration with family issues/events. Additional information will be reported at February and May Committee meetings. We are trying not to reinvent the wheel, but utilize what we have in place. Steve is in Washington D.C. now meeting with Congressmen to discuss Utah and national IDEA issues; to have federal law state that parents must be notified of all communication options (ASL, cued speech, spoken language) and have school districts be in charge of CI mapping (there is currently a school exclusion in federal law). Many Utah school districts have audiologists so the mapping would probably go through them. USDB had previously tried this, but insurance companies would not cover their services as they were a "mobile unit". Entities that are not in a brick and mortar building are not covered. Paula Pittman does not know if they can overcome that aspect.

Paula Pittman is working with Hands and Voices and interviewing parents to implement a program like Guide By Your Side. They will be using tele-intervention, phone and face to face appointments. They are working out the details and payment. USDB will fund the pilot and hopefully they will be able to grow the program. They are starting with four families; they will represent all of the methodologies and parents can contact those families once they are enrolled. This will start in February/March, 2014.

Public Meetings Act

Mandated annual training was presented by Lyle Odendahl, Assistant Attorney General with the Utah Department of Health. See handouts for more information. Government in the sunshine is the best form of government. This Act applies to public bodies; those bodies/committees created in statute or rule and have some advisory or decision making power; applies when a meeting is convened, called for the express purpose of

acting on business. We must have a quorum (majority) to vote. Public notices must be posted 24 hours in advance on the Utah Public Notice website with a *specific* agenda (<http://pmn.utah.gov>). Our Committee should not have a need for an emergency meeting, but if we do, call Lyle prior to scheduling. Written, pending minutes must be available within 30 days in draft format. Once approved by the committee at the next scheduled meeting, the minutes become official. Replacing the draft minutes with the final minutes is appropriate and must be done within 3 days of approval. Meetings must be recorded, and must have speakers identify themselves when speaking (for guests). Complete, unedited audio must be on the website within 3 days of the meeting. It must include substance of all matters discussed. Votes must be recorded by individual member. You may note as chair that “everyone in attendance has voted in the affirmative”. There must be a procedure in place for the approval of minutes. Electronic meetings are encouraged, but you must have a rule in place. If anyone joins by phone it makes it an electronic meeting. Open meetings are to allow the public to listen and find out what is going on, not necessarily to let the public speak. Email votes and telephone votes are not allowed. All voting must take place at a meeting. See page six of the statute for texting other members during a meeting; you can text each other when you are not convening an open meeting, but you may not make decisions that way. If you need to close a meeting (i.e.: discuss the character, professional confidence, or medical/physical health of an individual) contact Lyle first. If you violate the open meetings act (knowingly or intentionally) it is a Class B Misdemeanor. Dr. Dick asked about voting on new items discussed. If we discuss something new then we can’t vote until the next meeting. If you are going to vote upon it at the next meeting it needs to be on the agenda. In regards to voting today for Dr. Page to represent PCH on this committee, if it was clear enough on the agenda that we are going to try and select someone then it is fine to vote now. It was decided that we have given sufficient public notice to vote on Dr. Page today.

New Business

Dr. Page reported on the initial Pediatric Deaf and Hard of Hearing Collaborators Group meeting held last week at PCH, created to bring together any professional individual involved in the care of children. They had over 40 attendees representing 13 agencies. As a result of various presentations, information was compiled that individuals thought could be used to improve collaboration and services. Committees were formed and action items were listed. A proposal to Dr. White/NCHAM to initiate global education for pediatric hearing loss that would provide uniform education/resources for parents all along the spectrum and to pilot this education in Utah. It could be a supplementary option for professionals to help educate patients, and would reduce non-billable time (noting that 40% of time spent with cochlear implant doctors is non-billable time). This could standardize some processes they do and say every day and give parents additional resources thereby decreasing their dependency on professionals. This global education is in the initial stages; if anyone is interested in more information, please contact Dr. Page. Dr. Randall wondered if that education would be a redundancy. Dr. Page has not had that discussion yet, just proposing the exploration of the idea. We want to collaborate those services statewide - maybe tie to NCHAM, but we need to get together and discuss and see where things will cross over. Dr. McVicar asked if this was a PCH endeavor. Dr. Page initiated it and brought it up with Utah State University/NCHAM. Dr. Dick mentioned that we will have to define the role of this committee, adjunctive to what we do, since that is not the primary role of this committee. Dr. Randall just wants to make sure that their effort compliments our efforts. Charlene noted that the Medical Home Portal will be a good resource if they are looking for a place for parent information. This could also be included on the Pediatric EMRs. Charlene also mentioned that they have hired a new medical writer for the Medical Home Portal who will be updating module by module. Now is the time to have them update information if necessary and to make sure the CMV information is up-to-date.

Nomination for Dr. Page as a Consultant and voting member of the Utah Newborn Hearing Screening Committee (representing audiology and PCH audiology clinics) was opened. Nomination was made by Charlene, Seconded by Dr. Jolma. A majority of the committee was present, as required. All present voted

individually in the affirmative. Dr. Page accepted this Committee assignment. Nita will need his Vitae to send to UDOH.

Next meeting will be held February 11, 2014.

Adjourned by Dr. Dick at 11:00, motion to adjourn was made and seconded.

Mark your calendars for the 2014 meetings: February 11, May 13, August 1, and November 18. All meetings will be held from 9-11am at the Utah Dept. of Health, CSHCN Building, 44 Mario Capecchi Dr, SLC, Conference Rooms C-D.

FYI—You may subscribe to notices regarding this Committee on the Utah Public Notice website with instructions at <http://pmn.utah.gov> . Agendas will also be posted on that website at least 24 hours prior to the scheduled meeting.